

## SUDEP Action

Registered Charity No.  
1164250 (England & Wales)  
SC047223 (Scotland)  
[www.sudep.org](http://www.sudep.org)

## Linked with Epilepsy Bereaved

(working names SUDEP Action  
& SUDEP Action Scotland)

## Annual report and financial statements

For the year ended 31 March 2019

Chapman Worth Limited  
6 Newbury Street  
Wantage  
Oxfordshire  
OX12 8BS

# SUDEP Action & linked charity Epilepsy Bereaved

## CHARITY INFORMATION

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<b>Director</b>	Jane Hanna OBE
<b>Trustees</b>	John Hirst (Chair) Susan Allen Simon Lees Mark Phillips Alex Stirling Graham Faulkner Mike Kerr Rachel Shah Stephen Brown
<b>Charity No.</b>	1164250 (England & Wales) SC047223 (Scotland)
<b>Website</b>	<a href="http://www.sudep.org">www.sudep.org</a>
<b>Address for correspondence</b>	SUDEP Action 18 Newbury Street Wantage Oxfordshire OX12 8DA
<b>Accountants</b>	Chapman Worth Limited 6 Newbury Street Wantage Oxfordshire OX12 8BS
<b>Bankers</b>	HSBC Plc 24 Market Square Witney Oxfordshire OX28 6BG  Barclays Bank PLC Marcham Road Abingdon OX14 1UB

# SUDEP Action & linked charity Epilepsy Bereaved

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## **TRUSTEES' REPORT**

### **For the year ended 31 March 2019**

The trustees present their report and accounts for the year ended 31 March 2019.

The accounts have been prepared in accordance with the accounting policies set out in note 1 to the accounts and comply with the charity's governing document and the Statement of Recommended Practice, "Accounting and Reporting by Charities in accordance with the Financial Reporting Standard for Smaller Entities" (effective January 2015).

The report that follows is from the Board of Trustees of SUDEP Action for work undertaken by the charity as an unincorporated charity for the year to 31 March 2019.

### **Structure, Governance and Management**

The Registered Charity name is SUDEP Action. The Charity Registration number 1164250 (England and Wales) and SC047223 (Scotland) was constituted under a Declaration of Trust dated 14 October 2015 as a charitable incorporated organisation (CIO). The Charity is linked by the Charity Commission to the Registered Charity Epilepsy Bereaved (Charity Registration number 1164250), which was constituted under a Declaration of Trust dated 14 October 1995 as an unincorporated charity which adopted SUDEP Action as a working name in January 2013. The trustees of the Board of both charities are the same. Administering the charity as a CIO provides benefits in relation to employing staff, leasing property and entering into contracts. The linking of the two charities protects SUDEP Action from loss of legacy income in the future.

### **Board of Trustees**

John Hirst CBE (appointed Chair July 2018)

Professor Mike Kerr (Vice Chair) (appointment renewed as member of Board November 2018)

Rachel Shah (Treasurer)

Susan Allen

Professor Stephen Brown

Graham Faulkner

Simon Lees (appointment renewed as member of Board November 2018)

Mark Phillips

Alex Stirling (appointment renewed as member of Board November 2018)

SUDEP Action has a policy that 50% of the trustees should have direct experience of Sudden Unexpected Death in Epilepsy (SUDEP) and use their experience and knowledge to benefit the charity.



SUDEP Action recruits for trustee positions using a variety of methods, including internet recruitment sites, recommendation, and occasionally press. Appointments are recommended to the trustees and agreed by resolution at a special meeting normally after interview with two trustees and the CEO.

The projects of the charity are, where appropriate, supported by scientific advisory groups including a UK development group of doctors, nurses and people with epilepsy who support the SUDEP and Seizure Safety Checklist and an expert panel which provides advice to our support team for families after a death.

The report that follows covers our mission, why we exist, a summary of our achievements during the reporting year and the full report of how we spend our funds to tackle deaths and support families.

## Our Mission

SUDEP Action aspires to stop unnecessary deaths from epilepsy. We represent the voice of the bereaved and prioritise the acceleration of good practice as well as learning from deaths. Changing and saving lives through putting people, life-saving knowledge and support first is our priority because of the need to accelerate stopping of deaths.

## Why?

At least 21 people die from an epilepsy death each week and 21 communities are suddenly bereaved; nearly half can be prevented. Good practice is not always followed, there are huge gaps in knowledge in this area.

Over 22,000 people are reported as having died from epilepsy in the UK since five women launched Epilepsy Bereaved at a memorial service in London in 1996. This may underestimate the true figure.

**1 in 20 people will have a seizure in their life-time, whilst 600,000 in the UK live with epilepsy.** This is an issue which, although a mostly invisible disability, is likely to touch us all during our life-time.

10 deaths each week are in the young, with epilepsy ranking in the top ten causes of deaths from treatable conditions.

Deaths have fallen for all other conditions, with epilepsy and neurological conditions the only exceptions.

Huge gaps in knowledge, commitment and ability to act persist despite national initiatives aimed at preventing deaths since 2002.

We know from nearly 800 experiences shared by the bereaved that we have already changed the culture. Half of all the bereaved in the UK were aware that epilepsy was not benign compared with just 1% in 2002. Through our work, the UK leads the world on this level of awareness and understanding of risk, but it is still staggering that over half of the bereaved experience the shock of not having been made aware that epilepsy is life-threatening. It is shocking that over half are still not being helped with explanations after a death, with many waiting many months for an inquest to report, and most are left with inadequate answers. 8% of deaths reported were in people who had not been diagnosed with epilepsy. Additionally, the reports show that the majority were unaware of epilepsy risks (including those linked to SUDEP) or how to reduce them, even though the information shared suggested the person with epilepsy faced medication and life style issues which suggested they were at risk before their death. These issues, as well as the lack of any system for doctors to be told about the death, lead to additional complexity and trauma in the aftermath of a death.

Families, carers and friends who whilst grieving are also looking for answers, are often angry and confused, and seek to turn private pain into public purpose as a tribute to the life of the person who died.

They struggle to understand why avoidable deaths that occur in one place and at one time, such as an airline disaster or a fire, attracts some public attention and concern, whilst SUDEP and other epilepsy deaths, still don't. The persistence of a culture that systematically downplays risk is a major contributor to deaths.

## How?

At SUDEP Action our focus is on changing that culture. Our Prevent21 campaign shines a light on this shocking disaster bringing it out of the shadows and to the public's attention. With a significant change of attitude, culture, and action towards epilepsy, many many lives CAN be saved.

We focus our impact on:

- Bereavement support:** SUDEP Action leads the world as a gold standard service that can be a life-line for the bereaved in trauma and can enable them to influence learning after a death.

*"About one month after Sam's death, I read an article which provided a number for who to contact if you had been affected by a death in epilepsy.....Without SUDEP Action, I know I wouldn't be here today. Their support has been above and beyond."*
- Keeping people safe:** Reaching professionals throughout the UK to enable learnings from deaths, and support with education, training and safety tools such as our **standardised health check for risk**, acclaimed for Patient Safety and for innovation in tackling mortality.
- Helping people stay safe:** Informing and empowering people to access the information and support they may not have otherwise had, to reduce risk and live well. Using our **digital self-management tool** to encourage and support people to check their own risk and self-advocate.
- Targeting prevention and cure:** Forging forward with our dedicated research into the cause and prevention of sudden deaths in people living with epilepsy. Including our unique reporting platform with the largest data set of lived experiences of the bereaved with them reporting therapeutic benefits on completion.
- Increasing public awareness:** By supporting organisations and communities in the UK and around the world with common messages and learning on SUDEP Action Day; and with SUDEP the Global Conversation.



There is so much more to do. We lead this work confident of the support for our work evidenced in these national and global awards:



## Our Impact this year

13,825 people were supported, over 2,000 more than in our last reporting year.

7,108 people were helped by personalised services addressing individual need.

6,717 people were supported by general educational material and training.

Whilst our services with the bereaved provides personal and highly specialist help for as long as needed, our innovative technology also enables personalised and meaningful engagement with people with epilepsy and participation in research by the bereaved who are difficult to reach.

793 people participated in research with the bereaved sharing their experiences through our Epilepsy Deaths Register. This confidential and supported environment creates an increasingly powerful data set for learning from deaths in the UK and around the world.

We worked with research teams across the UK during the year. We are pleased that our funding of a clinical trial of a wearable apnoea device with UCL and Imperial will be reporting next year after successful recruitment of a strong cohort of patients with epilepsy. Our partnership working continues to strengthen with centres across the UK including Newcastle University and Plymouth University as well as with clinical research groups at Cornwall NHS Foundation Trust and the Oxford Epilepsy Research Group. Research in 2018 found a reduced risk for patients using our SUDEP and Seizure Checklist. Deaths have been observed as falling in a local population in the South-West, with no deaths reported in the learning disability community.

84 organisations supported across the UK and in other countries with agreed messages and visuals to raise awareness.

43 organisations were brought together for a Prevent21 UK Summit to tackle epilepsy deaths.

Informed by the stories and recommendations of people at risk and the bereaved, the Summit reached consensus on key recommendations and priorities, and will be published in

a leading international medical journal reaching audiences around the world. Our work was endorsed by the All Party Parliamentary Group on Epilepsy and the Neurological Alliance. Leading an epilepsy coalition, we brought evidence to senior level meetings and a judicial review increasing awareness and successfully influencing some positive changes in policy.

Investing in our support service for traumatised families through a new part-time case worker service has been transformative enabling us to double the number of highly complex advocacy cases we support, and influencing learning from deaths and changes in clinical and organisational practice.

The success of our Prevent21 campaign has meant that we are in a position to progress the priorities identified in the Prevent 21 Summit. With additional funding we would be in a position to progress more speedily to stop unnecessary deaths.

## **Bereavement Support**

Support & telephone counselling sessions – 761

Families provided with advocacy – 25

Families who have participated in research via Epilepsy Deaths Register – 793

Enabling bereaved volunteers – 43

Enabling bereaved supporters - 780

The bereaved are always at the centre of what we do.

For over 21 years we have listened to and worked with the bereaved to develop our service. The support team run a specialised service around epilepsy related deaths; they have an in-depth knowledge and years of experience working in this complex field.

We know from our research that specialist advocacy integrated with specialist bereavement support can help. SUDEP Action aims to provide this using a holistic approach that uniquely provides what a generic service is unable to do.

We helped a family get information about the cause of a death from a hospital trust and provided research for a family to provide to a coroner investigating a possible SUDEP. We helped a family who had questions about how their child died but didn't want to meet or have direct contact with anyone from the Hospital Trust. We corresponded with the hospital to get the answers the family were looking for. Understanding what the family's aim was and the sensitive disclosure of the information to the family was achieved through our caseworker working closely with bereavement support.

We helped an Epilepsy Specialist Nurse who required information regarding a patient death – How was SUDEP the cause of death when a post mortem wasn't conducted? We sent information about her query as well as our support information to pass onto the family.



Our aim is to empower the bereaved to find the answers they need. The information and advice we provide is tailored to the individual. We are led by what families and individuals want and need and we aim not to superimpose a view of what that might be.

What is helpful to the bereaved after an epilepsy death?

(Source: Data from the Epilepsy Deaths Register)

<b>Finding answers</b>	<b>Help in understanding the investigation</b>	<b>Contact with others bereaved by epilepsy</b>	<b>Counselling</b>
<b>Someone to talk to</b>	<b>Learning about epilepsy related deaths</b>	<b>Getting involved with work of the charity</b>	<b>Meeting experts</b>
			<b>Other</b>

*"...I knew I could talk about how I felt and the devastation that followed seeing my little sister Jenny have her final seizure and then watching whilst her life support was turned off. They helped me find my way back from the dark hole I was heading towards because of the guilt I felt and try and make sense of why it happened and that I was not to blame and nor could I fix it, something I still deal with but I can cope now. On the first call I went from someone who could hardly talk, without crying to laughing at some of the memories. They are wonderful and have my admiration and total respect".*

Many families want to get involved. This can involve becoming a dedicated volunteer who regularly helps including hosting coffee clubs and engaging local GPs. We have learnt over 21 years working with the bereaved that it is vital that we can offer opportunities that do not require a regular commitment but that are still incredibly powerful. This may include sharing their inspirational stories to influence change.

*"Having had the devastating trauma of finding one's young adult son dead from 'Sudden unexpected death in Epilepsy', I am really glad to be a volunteer with the SUDEP Action charity, to try and prevent more deaths from Epilepsy occurring, by lessening the risks, and educating the medical profession to better communicate these risks to families. Glad too to help run local Coffee Club Support Groups for similarly bereaved parents to come together and share their deep sadnesses, and endeavour to help others coping with Epilepsy. From personal experience, this can help so very much."*

## Keeping people safe

654 people receive our professional e-news updates.

We provide training for medical teams around the UK.

*"Thank you for such an informative and inspiring talk. It has certainly highlighted to me what a significant topic this is, and I now feel it is my duty as the Lead GP here for Epilepsy to really take this forward and thoroughly review our register of patients, our recall and review system and to start educating patients more about SUDEP. The use of cases and those photos and stories of all those young people who have tragically died is a particular source of inspiration and really gave your talk a significantly deeper level of impact and importance, so thank you to all the families who have been involved for this too."*

GP lead for a University GP Service (following a Conference presentation)

707 clinicians were engaged with the SUDEP and Seizure Safety Checklist alone.

We involve doctors and nurses across community and acute care and involve people living with epilepsy in the development of our safety tools.

## Case Study SUDEP and Seizure Safety Checklist

*The project was pump-primed by Kt's Fund, a local fund set up by the parents of Katie, a young trainee nurse who died of SUDEP whilst waiting for an appointment. Developed in partnership with Cornwall NHS Foundation Trust using a 9-year quality improvement drive methodology, it encourages positive discussion of risk management with patients supporting the implementation of national guidelines and recommendations, from high profile medical-legal rulings. Working locally, it has brought families, the local community and professional champions together. Research we commissioned found many people who died had worsening risk factors before they died. Rates of communication have remained as low as 4 - 15% in the 12 years since UK national guidelines recommended that a discussion about SUDEP was essential in 2004. The outcome has been safety tools welcomed by clinicians and people with epilepsy. Using the Checklist has raised discussions from 10% to 80% of all people within epilepsy services and has reduced risks in patients. Deaths have been observed as falling, with no deaths reported in the learning disability community. A digital tool for patients has now been developed with 3,500 people with epilepsy in UK already registered users.*

Since 2015 the Checklist has been supported by a UK-wide development team of GPs, experts and people living with epilepsy. It is regularly reviewed to ensure it considers latest research and thinking on risk in epilepsy.

*"I have first-hand experience in losing a son to epilepsy & none of my colleagues previously realised people could die - nobody had heard of SUDEP - so now they understand the importance of using tools like the Checklist to monitor risk"*  
(clinician and bereaved parent)



*"I always ask the patients consent to complete the checklist and explain what I am doing. I put emphasis on the positive results and we discuss how they can modify factors that potentially would put them at increased risk. I have not had a negative response."  
(epilepsy Specialist nurse midwife)*

Our formal collaboration agreements with NHS Partners, Universities and patient organisations:

**SUDEP and Seizure Safety Checklist:** Cornwall Partnership NHS Foundation Trust

**EpSMon:** Cornwall Partnership NHS Foundation Trust, Royal Cornwall Hospitals

**WADD Clinical Trial:** University College London (UCL) and Imperial College London

**Epilepsy Deaths Register:** Epilepsy Ireland

## Helping people stay safe

3,500 people received our information brochures.

3,200 people registered with our EpSMon epilepsy self-monitor App, which is proven to reach people at known risk with personalised reports and encouragement to present to GPs when their epilepsy and risk is not well controlled.

EpSMon is a smartphone App which helps patients to monitor risk factors from seizures and keep track of their general well-being. In 2017 it was chosen as one of eight innovations for the NHS Innovation Accelerator Programme and was used as an example of good practice in the NHS 70<sup>th</sup> year anniversary video.

EpSMon is a digital version of the SUDEP and Seizure Safety Checklist which was developed by SUDEP Action, Cornwall Partnership NHS Foundation Trust and Royal Cornwall Hospitals as a clinical tool. Our SUDEP and Seizure Safety Checklist has proved itself in reducing risk in people living with epilepsy.

*"I'm sure Benn would have used [EpSMon]. He had no warning of his seizures & his doctors told me he took a responsible approach, looking at every option. If this app had been available, maybe the ending of this story may have been very different"*

**A supporter who raises awareness in memory of her son**



## Targeting prevention and cure

### Epilepsy Deaths Register

Our unique Epilepsy Deaths Register (EDR) offers the bereaved an online research platform to share their experiences and strengthens the voice of the bereaved.

The Epilepsy Deaths Register has proved to be therapeutic to the bereaved who are able to place their experiences in the knowledge that this will help learning for the future. The Register is vital in confirming that the experiences of the families after a death are of equal significance for learning by researchers and clinicians, as the experiences in the lead up to the death and in flagging key areas of concern. These include poor communication before and after a death; poor reporting of deaths; and learnings of factors that may have contributed to death.

### The WADD Project (Wearable Apnoea Detection Device for people with epilepsy)

Most sudden deaths are at night when most seizures are unwitnessed. Having the ability to alert someone to come and help during a life-threatening episode may be protective. This needs to be part of a risk assessment and care plan worked up with the person with epilepsy aimed at improving safety and wellbeing. SUDEP Action is funding and supporting research at UCL and Imperial College to research a device that has already confirmed high sensitivity and low false alarm rates for people living with epilepsy and improve technology in this field.

The innovation has since attracted investment of 2 million euros from the European Research Council to the engineer at Imperial College enabling development of this device. SUDEP Action is the Patient and Public Involvement lead on this vitally important project which runs to 2020.

The ultimate aim is to produce a minute device which could be worn all the time by people at high risk of SUDEP. Maybe one day, it could even be implanted in children with epilepsy to keep them safe for life.

*"I really believe that the WADD has the potential to save lives. I informed all my sponsors about the project and they were even more pleased to know their money would go directly towards it"*

**A supporter who raises funds in memory of his father**

## Increasing Public Awareness

Prevent21 has enabled us to reach new audiences outside of the epilepsy community. This is in addition to the increased public awareness from our leadership of global SUDEP Action Day every year.

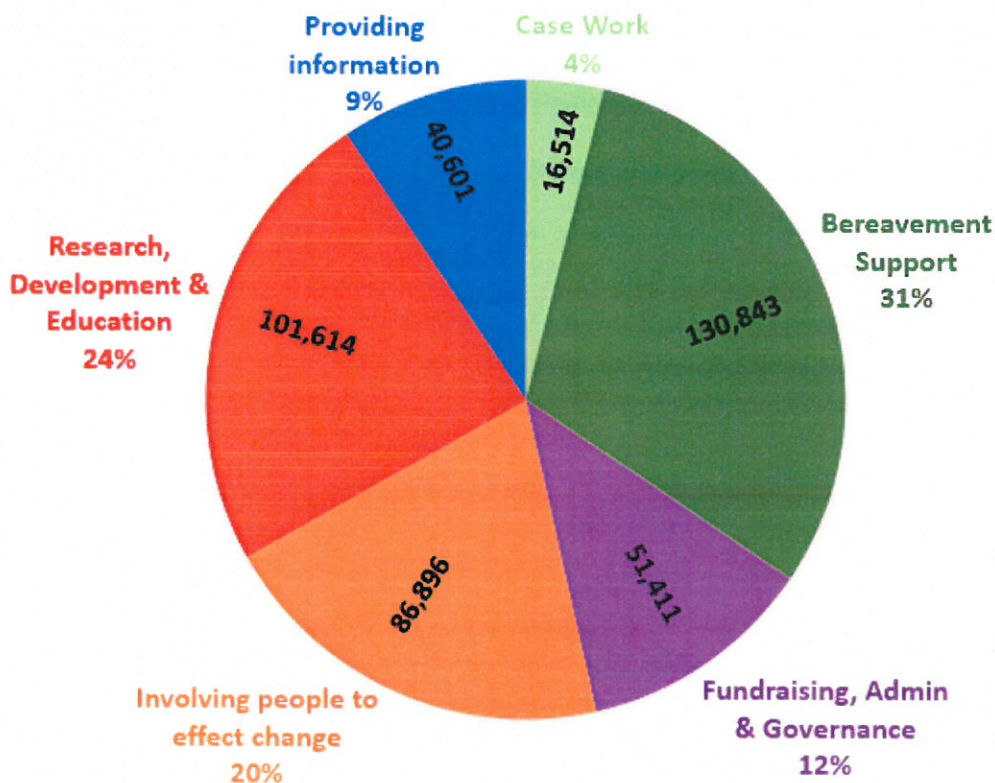
We saw an increase in users of our website from 100,000 to over 140,000 this reporting year.

We also work with umbrella organisations to strengthen our influence. We are active members of the Neurological Alliance and provide the Secretariat for the All Party Parliamentary Group on Epilepsy. We work with epilepsy organisations in Scotland and are active members of the Cross-Party Parliamentary Group for Epilepsy and the Epilepsy Consortium.

We are members of the IBE (International Bureau for Epilepsy) and ILAE (International League Against Epilepsy). We have partnerships with Epilepsy Action Australia and Epilepsy Ireland. There is increasing demand for our services and projects from other countries.

## Financial Matters

Our expenditure during the year of £427, 879 was apportioned as follows:





## Income and reserves

The charity's income was £480,224 (compared with £443,143 during 2017/18, £431,122 during 2016/17 and £395,413 during 2015/16). £20,479 of income during 2018/19 was restricted funding with the balance of all restricted funds held, including those funds from income received before this reporting year, totalling £77,328.

Thanks to supporters of the Prevent21 campaign as well as our regular donors our income is growing. Thanks also to the grant giving trusts that have supported us: **Alison Hillman Charitable Trust; Ammco Trust; Garfield Weston Foundation; Masonic Charitable Foundation; Mr and Mrs J A Pye's Charitable Settlement; St James's Place; The Adrian Swire Charitable Trust.**

The Prevent21 Summit was generously sponsored by Jon Manson and Rachel Shah.

Since our WADD appeal project (see page 10 for details) the researcher at Imperial College London has received a grant of €2 million to develop a wearable device by 2020. The WADD restricted fund has been used this reporting year by the researcher at Imperial College to collaborate with UCL on the clinical trial on WADD. The research team at UCL and Imperial College London requested a no cost 9 month extension of the project to July 2020 because of the opportunity to increase the power of the clinical trial and facilitate further technical improvements involving a further 50 to 75 patients. The remaining WADD reserves will be fully or substantially paid out to University College London and Imperial College London by July 2020 under the conditions of the research grants agreed with these universities and in accordance with the WADD appeal.

Restricted funds totalling £6,858 to support projects working with researchers and UK clinicians will be fully paid out 2019/20.

Our uncommitted funds or general funds stood at £162,823 at year end or just under 7 months of general fund expenditure. The Board of Trustees agreed the Board reserve policy of between 3 to 6 months income which is monitored monthly and kept under regular review at each Board meeting. Although our reserves position is more than adequate for current needs, we are facing unprecedented demand and will be recruiting 3 more permanent staff during 2019/20.

## Risk

Financial control is through an annual budgetary process and regular reporting to management and the Board.

The trustees continue to assess the risks faced by the charity and to propose actions to mitigate these risks. The trustees review these risks on an ongoing basis and satisfy themselves that adequate systems and procedures are in place to manage, mitigate or reduce the risks identified. Where appropriate, risks are covered by insurance. The

management team has a standard agenda item for reporting of significant variations and risks and the Chief Executive has regular liaison with the Chair of the charity where risks that arise in between Board meetings can be flagged and action taken.

The Board has three clinicians with skill sets to strengthen the Board in line with the charity strategy of even closer working with clinical teams across the UK.

## **The Future**

Our Prevent21 Summit prioritised SUDEP Action leading collaborative efforts to tackle epilepsy deaths.

Our direction is clear. Too many children of whatever age are dying unnecessarily. Parents and siblings too. Families and communities are left devastated by loss.

Our priority is rolling out our projects and services in the UK to as many people as possible who need these.

We also need to strengthen recognition of SUDEP Action as the first and best point of contact for the bereaved after a death, so that they can find us in a timely way. It is vital that the lessons from deaths are learnt and that the bereaved are treated fairly after a death.

The success of our Prevent21 campaign means that during the next year we can recruit new staff across philanthropy, research and projects. This is an exciting development that will further our ambition to pilot 'best practice interventions' across risk management and care after a death, initially in Oxfordshire with aim of providing a flagship model that can be replicated across the UK. Our solutions are easily scalable, and already shared in other countries. Our aspirations are without local, national or international boundaries.

With further development funding we can work with other centres to move quickly to meet need and deliver change.

### **During 2019/20 we will:**

- ❖ **Use the Prevent21 Summit consensus on priorities to inform SUDEP Action strategy and projects needed to tackle deaths**
- ❖ **Lead an epilepsy coalition to influence policy safeguards for continuous access to vital life saving medicines as one outcome of collaborative advocacy**
- ❖ **Bring evidence from the bereaved and people with epilepsy who are at risk to the attention of government and policy makers in the UK to influence policy**
- ❖ **Take forward a partnership with the Royal College of Pathologists to promote learnings of good practice after a death**



- ❖ Plan and recruit new staff with view to piloting place-based best practice intervention across risk management and care after a death in Oxfordshire in partnership with Oxford Epilepsy Research Group
- ❖ Invest in strengthening our service for traumatised people and learnings from death by investing in our new case worker role as part of our specialist support for the bereaved
- ❖ Recruit a new trustee with professional community based medical expertise and experience
- ❖ Spread good practice globally building power of SUDEP Action Day and roll-out our SUDEP and Seizure Safety tools in Australia working with our partner Epilepsy Action Australia
- ❖ Provide ongoing patient and public involvement for research projects including a clinical trial and development of a wearable device on people with epilepsy, to alert to an acute episode that could kill

Signed for and on behalf of the Board of Trustees



**J Hirst CBE Chair of Trustees**

## **Summary of the Year – Message from CEO**

We are in a period of growth, creating opportunities to build on existing services and develop new ones using our innovative model to tackle painful systematic gaps that contribute to avoidable deaths. Progress continues, but challenges have increased with worsening of risks for families with lived experience of epilepsy.

The problem has become more urgent since NHS funding for health checks for people with epilepsy were cut in the community in 2013 and also as medicines shortages for people with epilepsy have worsened this reporting year.

Embracing the power of communities and innovating with technology has enabled SUDEP Action to serve the cause of preventing deaths and rebuilding lives. SUDEP Action has continued to respond creatively to the needs we have identified and to look for new ways to support the community. We have done this without any statutory funding.

SUDEP Action is a dynamic organisation, always ready to review which opportunities we embrace and which challenges to tackle. We were able to lead an epilepsy coalition campaign to influence some improvements to policy with view to protecting continuity of access to medicines to the benefit of people with epilepsy and all people that need medicines. We managed this in addition to our planned Prevent21 work programme of research and development to tackle deaths and support clinicians and families.

Our team has grown this year to 11, in total 8 full-time equivalent staff. We have moved premises to facilitate further growth as demands on the charity increase. This will help us reach more people and more professionals as well as spread our message across the UK and beyond. We led extensive individual and group work across the whole charity leading to a restructure of the organisation; an upskilling of the team; integration of new members of the team with all involved in the development of our mission, core activities and values as a charity. Our values were renewed this year working across the whole team of staff and Board as seeking to be courageous, impactful, pioneering, collaborative and at all times compassionate.

We have welcomed increasing interest in the work we are doing from across the globe and have shared best practice.

I would like to thank all those who volunteer for SUDEP Action and all our community fundraisers and generous individuals who support us through legacies and donations. We have also enjoyed amazing support this year from our UK-wide clinical and cross-party political network.

It has been a tremendous privilege to work alongside dedicated colleagues across our Board and staff team.

Jane Hanna OBE  
CEO, SUDEP Action

**INDEPENDENT EXAMINER'S REPORT TO THE TRUSTEES**

**For the year ended 31 March 2019**

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I report on the accounts of the Trust for the year ended 31 March 2019, which are set out on the pages 21 to 28.

**Respective responsibilities of the trustees and examiner**

The charity's trustees are responsible for the preparation of the accounts. The charity's trustees consider that an audit is not required for this year under section 144(2) of the Charities Act 2011 (the 2011 Act) or under Regulation 10(1)(a) of the Charities Accounts (Scotland) Regulations 2006 (the 2006 Regulations) and that an independent examination is needed. The charity is preparing accrued accounts and I am qualified to undertake the examination by being a qualified member of the ICAEW.

It is my responsibility to:

- (i) examine the accounts under section 145 of the Charities Act 2011 and under section 44(1)© of the Charities and Trustee Investment (Scotland) Act 2005 (the 2005 Act);
- (ii) to follow the procedures laid down in the general Directions given by the Charity Commission under section 145(5)(b) of the 2011 Act; and
- (iii) to state whether particular matters have come to my attention.

**Basis of independent examiner's statement**

My examination was carried out in accordance with general Directions given by the Charity Commission and is in accordance with Regulation 11 of the Charities Accounts (Scotland) Regulations 2006. An examination includes a review of the accounting records kept by the charity and a comparison of the accounts presented with those records. It also includes consideration of any unusual items or disclosures in the accounts, and seeking explanations from the trustees concerning any such matters. The procedures undertaken do not provide all the evidence that would be required in an audit, and consequently no opinion is given as to whether the accounts present a 'true and fair view' and the report is limited to those matters set out in the statement below.

**Independent examiner's statement**

In the course of my examination, no matter has come to my attention:

- (a) which gives me reasonable cause to believe that in any material respect, the trustees have not met the requirements to ensure that:
  - (i) proper accounting records are kept in accordance with section 130 of the 2011 Act and section 44(1)(a) of the 2005 Act and Regulation 4 of the 2006 Accounts Regulations; and
  - (ii) accounts are prepared which agree with the accounting records and comply with the accounting requirements of the 2011 Act and section 44(1)(b) of the 2005 Act and Regulation 8 of the 2006 Accounts Regulations; or
- (b) to which in my opinion, attention should be drawn in order to enable a proper understanding of the accounts to be reached.

  
**Anna Chapman FCA**

**Chapman Worth Limited**

6 Newbury Street

Wantage

Oxfordshire

OX12 8BS

Dated.....

8/11/20

## SUDEP Action

Registered Charity N°: 1164250 (England & Wales), SC047223 (Scotland)

Linked Charity: Epilepsy Bereaved (established 1995)

### Statement of Financial Activities For the year ended 31 March 2019

		SUDEP Action Unrestricted Funds 2019	SUDEP Action Designated Funds 2019	SUDEP Action Restricted Funds 2019	SUDEP Action Total Funds 2019	SUDEP Action Total Funds 2018
	Note	£	£	£	£	£
<b>Income from</b>						
Donations and legacies	2	423,424	12,500	20,479	456,403	402,090
Charitable activities	3	3,317	-	-	3,317	20,391
Other trading activities	4	19,376	-	-	19,376	20,229
Investments	5	1,128	-	-	1,128	433
<b>Total incoming resources</b>		<b>447,245</b>	<b>12,500</b>	<b>20,479</b>	<b>480,224</b>	<b>443,143</b>
<b>Resources Expended</b>						
Raising funds	6	50,645	-	871	51,516	48,869
Charitable activities	7-8	312,388	-	63,975	376,363	337,261
<b>Total resources expended</b>		<b>363,033</b>	<b>-</b>	<b>64,846</b>	<b>427,879</b>	<b>386,130</b>
<b>Net income/(expenditure)</b>		<b>84,212</b>	<b>12,500</b>	<b>(44,367)</b>	<b>52,345</b>	<b>57,013</b>
<b>Transfers between funds</b>	12	(75,000)	75,000	-	-	-
<b>Net movement in funds</b>		<b>9,212</b>	<b>87,500</b>	<b>(44,367)</b>	<b>52,345</b>	<b>57,013</b>
Total funds brought forward 1 April 2018 (2017)		153,611	-	121,695	275,306	218,293
<b>Total funds carried forward 31 March 2019 (2018)</b>		<b>162,823</b>	<b>87,500</b>	<b>77,328</b>	<b>327,651</b>	<b>275,306</b>

The notes on pages 18 to 23 form part of these financial statements.



## SUDEP Action

Registered Charity N°: 1164250 (England & Wales), SC047223 (Scotland)  
Linked Charity: Epilepsy Bereaved (established 1995)

### Balance Sheet as at

	Note	31 March 2019 SUDEP Action Unrestricted Funds	31 March 2019 SUDEP Action Designated funds	31 March 2019 SUDEP Action Restricted Funds	31 March 2019 SUDEP Action TOTAL	31 March 2018 SUDEP Action TOTAL
		£	£	£	£	£
<b>Current Assets</b>						
Prepayments		3,044	-	-	3,044	2,566
Debtors		-	-	-	-	8,778
Accrued Gift Aid		3,482	-	41	3,523	12,626
Cash at bank and in hand		175,823	87,500	77,287	340,610	267,303
		<u>182,349</u>	<u>87,500</u>	<u>77,328</u>	<u>347,177</u>	<u>291,273</u>
<b>Creditors: amounts falling due within one year</b>	11	(19,526)	-	-	(19,526)	(15,967)
<b>Net Assets</b>		<u><u>162,823</u></u>	<u><u>87,500</u></u>	<u><u>77,328</u></u>	<u><u>327,651</u></u>	<u><u>275,306</u></u>
<b>Funds</b>						
Unrestricted Funds	12	162,823	-	-	162,823	153,611
Designated Funds	12	-	87,500	-	87,500	-
Restricted Funds	12-13	-	-	77,328	77,328	121,695
		<u><u>162,823</u></u>	<u><u>87,500</u></u>	<u><u>77,328</u></u>	<u><u>327,651</u></u>	<u><u>275,306</u></u>

The financial statements were approved by the Board of Trustees on 02/01/2020 and signed on its behalf by:



John Hirst  
Chair of Trustees

The notes on pages 23 to 28 form part of these financial statements.

**SUDEP Action**  
**Registered Charity N°: 1164250 (England & Wales), SC047223 (Scotland)**  
**Linked Charity: Epilepsy Bereaved (established 1995)**

**Notes to the Financial Statements  
for the Year Ended 31 March 2019**

**1 Accounting policies**

**Company Information**

Sudep Action is a Charitable Incorporated Organisation registered with the Charities Commission for England and Wales and with The Scottish Charities Register (OSCR). Epilepsy Bereaved is the linked charity of SUDEP Action. Epilepsy Bereaved is an unincorporated charity registered with the Charities Commission for England and Wales and The Scottish Charities Register (OSCR).

**a) Basis of preparation**

The accounts have been prepared in accordance with FRS102 "The Financial Reporting Standard applicable in the UK and Republic of Ireland" ("FRS102"), "Accounting and Reporting by Charities" the Statement of Recommended Practice for charities applying FRS102, Trustee Investment (Scotland) Act 2005, Charities Accounts (Scotland) Regulations 2006. The charity is a Public Benefit Entity as defined by FRS102.

The accounts are prepared in sterling, which is the functional currency of the charity. Monetary amounts in these financial statements are rounded to the nearest £1.

The financial statements have been prepared to give a 'true and fair' view and have departed from the Charities (Accounts and Reports) Regulations 2008 only to the extent required to provide a 'true and fair view'. This departure has involved following Accounting and Reporting by Charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS102) issued on 16 July 2014 rather than the Accounting and Reporting by Charities: Statement of Recommended Practice effective from 1 April 2005 which has since been withdrawn.

The financial statements have been prepared under the historic cost convention. The principle accounting policies adopted are set out below.

These accounts have been prepared using branch accounting to show the results of both SUDEP Action and Epilepsy Bereaved. CIO SUDEP Action was established in November 2015 to take forward the work of the unincorporated association Epilepsy Bereaved (formerly CCEW reg 1050459). The Charity Commission linked the two charities on 2 March 2017. Epilepsy Bereaved had no activity during the year ended 31 March 2019 and the comparative year.

**b) Going concern**

At the time of approving these accounts, the trustees have a reasonable expectation that the charity has adequate resources to continue in operational existence for the foreseeable future. Thus the trustees continue to adopt the going concern basis of accounting in preparing the accounts. Epilepsy Bereaved ceased operations as of the 31 March 2019. The assets of Epilepsy Bereaved will be transferred to SUDEP Action before being closed.

**c) Charitable funds**

Unrestricted funds are available to spend on activities that further any of the purposes of the charity. Designated funds are unrestricted funds of the charity which the trustees have decided at their discretion to set aside to use for a specific purpose. Restricted funds are donations which the donor has specified are to be solely used for particular areas of the charities work or for specific projects being undertaken by the charity. The aim and use of each restricted fund is set out in note 12 to the financial statements.

**d) Incoming resources**

Items of income are recognised and included in the accounts when all of the following are met:

- the charity has entitlement to the funds;
- any performance conditions attached to the item(s) of income have been met or are fully within the control of the charity;
- there is sufficient certainty that receipt of the income is considered probable; and
- the amount can be measured reliably.

For legacies, entitlement is taken the earlier of:

- the charity being notified of an impending distribution; or
- the legacy being received.

Other voluntary income and donations are included in the accounts when received.

Fundraising income is generated by the charity's supporters mainly through sponsored events.

**e) Resources expended**

All expenditure is included on an accruals basis. Expenditure is recognised once there is a legal or constructive obligation to make a payment to a third party, it is probable that settlement will be required and the amount of the obligation can be measured reliably. Expenditure is classed under the following headings:

- Costs of raising funds comprise those incurred in seeking and acquiring voluntary contributions as well as the costs relating to the small scale sales of branded goods.
- Expenditure on charitable activities includes the Costs of activities undertaken to further the purpose of the charity and their associated support Costs

**SUDEP Action**

Registered Charity N°: 1164250 (England & Wales), SC047223 (Scotland)

Linked Charity: Epilepsy Bereaved (established 1995)

**Notes to the Financial Statements  
for the Year Ended 31 March 2019**

**1 Accounting policies, continued****f) Non-exchange transactions and foreign currency conversions.**

Google provide a grant to meet their associated publicity costs (see notes 2 & 8). The currency unit is US dollars, which is converted to sterling at the prevailing exchange rate at each month end.

**g) Allocation of support costs**

Support costs are those functions that assist the work of the charity but do not directly undertake charitable activities. These costs have been allocated between costs of raising funds and expenditure on charitable activities. The basis on which support costs have been allocated are set out in note 7.

**h) Research grants**

A grant of £12,500 was made to the Royal College of Paediatrics and Child Health for the "Suveillance of Deaths in children with epilepsy on the BPSU reporting scheme Nov 2016-Nov 2017.

**i) Taxation**

The charity is an exempt approved charity under the Income and Corporation Taxes Act 1988. All its charitable trading activity is used solely for its charitable purposes and any non-charitable trading falls below the statutory thresholds. Tax payable 2018: nil (2017: nil). Most of the charity's income is exempt from or outside the scope of VAT, and the trustees do not see any advantage to be gained by voluntary registration. Unrecoverable VAT is included in relevant costs in the statement of financial activities.

**j) Cash and cash equivalents**

Cash and cash equivalents include cash in hand, deposits held at call with banks, other short-term liquid investments with original maturities of three months or less, and bank overdrafts. Bank overdrafts are shown within borrowings in current liabilities.

**k) Tangible fixed assets and depreciation**

The charity does not have any fixed assets. The trustees consider the provision of office equipment to be part of the running costs of the organisation and it is written off in the year of purchase.

**l) Debtors**

Trade and other debtors are recognised at the settlement amount. Prepayments are valued at the amount prepaid after taking account of any trade discounts due.

**m) Creditors and provisions**

Creditors and provisions are recognised where the charity has a present obligation resulting from a past event that will probably result in the transfer of funds to a third party and the amount due to settle the obligation can be measured or estimated reliably. Creditors and provisions are normally recognised at their settlement amount after allowing for any trade discounts due.

**n) Financial instruments**

The charity only has financial assets and financial liabilities of a kind that qualify as basic financial instruments. Basic financial instruments are initially recognised at transaction value and subsequently measured at their settlement value.

**o) Pensions**

The charity operates two defined contribution pension schemes which includes both employer and employee contributions. Contributions are charged in the accounts as they become payable in accordance with the rules of the schemes.

**SUDEP Action**

Registered Charity N°: 1164250 (England &amp; Wales), SC047223 (Scotland)

Linked Charity: Epilepsy Bereaved (established 1995)

**Notes to the Financial Statements  
for the Year Ended 31 March 2019**

	<b>Unrestricted Funds £</b>	<b>Designated Funds £</b>	<b>Restricted Funds £</b>	<b>TOTAL 2019 £</b>	<b>TOTAL 2018 £</b>
<b>2 Donations and legacies</b>					
Donations	37,382	12,500	20,479	70,361	67,987
Grants	30,250	-	-	30,250	70,703
Non-Exchange Grants	-	-	-	-	42,569
Gift Aid	3,941	-	-	3,941	18,686
Legacies	4,614	-	-	4,614	30,000
Fundraising donations	346,375	-	-	346,375	169,065
Collecting boxes	862	-	-	862	3,079
	<b>423,424</b>	<b>12,500</b>	<b>20,479</b>	<b>456,403</b>	<b>402,089</b>
<b>3 Charitable activities</b>					
Annual charity conference	3,037	-	-	3,037	4,968
Fees receivable	280	-	-	280	15,423
Contractual income *	-	-	-	-	-
	<b>3,317</b>	<b>-</b>	<b>-</b>	<b>3,317</b>	<b>20,391</b>
<b>4 Other trading activities</b>					
Fundraising sales	15,922	-	-	15,922	18,785
Sale of goods	3,454	-	-	3,454	1,444
	<b>19,376</b>	<b>-</b>	<b>-</b>	<b>19,376</b>	<b>20,229</b>
<b>5 Investments</b>					
Interest Receivable	1,128	-	-	1,128	433
	<b>1,128</b>	<b>-</b>	<b>-</b>	<b>1,128</b>	<b>433</b>

\* Contractual income relates to the EpSMon project (see note 12a, Cornwall Fund)

Notes to the Financial Statements  
for the Year Ended 31 March 2019

	Unrestricted Funds £	Restricted Funds £	TOTAL 2019 £	TOTAL 2018 £
<b>6 Raising funds</b>				
Fundraising Expenses	33,657	871	34,528	35,695
Support costs	16,988	-	16,988	13,174
	<b>50,645</b>	<b>871</b>	<b>51,516</b>	<b>48,869</b>
<b>7 Charitable activities</b>				
Direct charitable expenditure	282,283	63,975	346,258	302,239
Governance costs	1,559	-	1,559	1,520
Support costs	28,546	-	28,546	33,502
	<b>312,388</b>	<b>63,975</b>	<b>376,363</b>	<b>337,261</b>

Governance costs consist of the independent examiner's fee, costs of trustees' meetings, and reconstitution costs, all as set out in Note 8 below.

Support costs consist of staff costs not directly attributable to charitable expenditure and related office overheads, and are apportioned on the basis of staff resources committed to fundraising and charitable activities proportionately.

**8 Charitable activities and support costs**

Postage and Stationery	3,934	64	3,998	4,071
Telecommunications	2,991	-	2,991	2,360
Printing & Publicity	6,985	1,680	8,665	11,729
Non-Exchange Publicity	-	-	-	42,532
Salaries & National Insurance	188,412	20,854	209,266	204,234
Pension Scheme Contributions	4,256	-	4,256	2,082
Consultancy & other staff costs	1,950	-	1,950	9,630
Travel, Accommodation & Subsistence	6,026	707	6,733	6,399
Research grants	-	40,620	40,620	12,500
Affiliations to Other Groups	1,061	-	1,061	789
Development of Web Site	9,541	-	9,541	5,961
Cost of Support Group Meetings	287	-	287	2,275
Bank Charges	108	-	108	51
Training	174	-	174	140
Office Costs, including Insurance	17,749	-	17,749	17,504
Conferences & Seminars	20,796	-	20,796	12,122
Sundry Expenses	660	-	660	537
Legal Costs	327	-	327	-
IT Costs	10,154	50	10,204	-
Equipment Purchases	9,971	-	9,971	-
Independent Examiner's Fee	835	-	835	825
Cost of Trustees' meetings	724	-	724	1,520
Office Move	25,447	-	25,447	-
	<b>312,388</b>	<b>63,975</b>	<b>376,363</b>	<b>337,261</b>

**9 Staff Costs including Pension Scheme Contributions**

Salaries & National Insurance	201,538	20,854	222,392	215,878
Pension Scheme Contributions	4,256	-	4,256	2,082
	<b>205,794</b>	<b>20,854</b>	<b>226,648</b>	<b>217,961</b>

There was an average of 8.9 employees (FTE) during the year (2018: 6.4)

No employee earned over £60,000 in the year (2018: nil).

The charity operates two defined contribution pension schemes. The assets of the schemes are held separately from those of the charity in independently administered funds. Costs shown are employer contributions.

**SUDEP Action**

Registered Charity N°: 1164250 (England &amp; Wales), SC047223 (Scotland)

Linked Charity: Epilepsy Bereaved (established 1995)

**Notes to the Financial Statements  
for the Year Ended 31 March 2019****10 Trustee expenses**

The Trustees received no remuneration during the year (2018: nil).

1 Trustee was reimbursed a total of £307 (2018: 3 trustees £522) for travel expenses.

**11 CREDITORS: amounts falling due within one year**

	Unrestricted Funds £	Restricted Funds £	TOTAL 2019 £	TOTAL 2018 £
Trade Creditors	6,380	-	6,380	2,711
Sundry Creditors	-	-	-	1,234
Credit Card	-	-	-	503
Receipts in Advance	-	-	-	1,569
HMRC-PAYE/NI	4,692	-	4,692	4,293
Pension	854	-	854	689
Accrued Expenditure	7,600	-	7,600	4,968
	<u>19,526</u>	<u>-</u>	<u>19,526</u>	<u>15,967</u>

**12 Statement of funds**

	Note	Brought Forward £ Surplus/ (Deficit)	Incoming Resources £	Resources Expended £	Transfers In/(Out) £	Carried Forward £ Surplus/ (Deficit)
<b>Unrestricted funds</b>						
General fund		<u>153,611</u>	<u>447,245</u>	<u>(363,033)</u>	<u>(75,000)</u>	<u>162,823</u>
<b>Designated funds</b>						
Prevent21 projects		<u>-</u>	<u>12,500</u>	<u>-</u>	<u>75,000</u>	<u>87,500</u>
<b>Restricted funds</b>						
WADD		61,162	2,000	(12,530)	-	50,632
Cornwall	12a	(151)	-	-	151	-
LDA		2,724	-	(2,724)	-	-
Research		34,470	2,309	(29,770)	(151)	6,858
Epilepsy Death Register		23,490	8,170	(15,306)	-	16,354
Case Worker Project		-	5,000	(4,516)	-	484
Oxon Pilot Project		-	3,000	-	-	3,000
<b>Total</b>		<u>121,695</u>	<u>20,479</u>	<u>(64,846)</u>	<u>-</u>	<u>77,328</u>

**SUDEP Action**

Registered Charity N°: 1164250 (England &amp; Wales), SC047223 (Scotland)

Linked Charity: Epilepsy Bereaved (established 1995)

**Notes to the Financial Statements  
for the Year Ended 31 March 2019****13 Details of restricted funds and special projects****Designated Funds****Prevent 21**

Funding to support the Prevent 21 campaign which aims to support our dedicated programme of research and surveillance that brings knowledge to save lives now by shining a light on key risk factors, conversations, and actions. As well as, contributing to research to help in the near future.

**Restricted Funds****WADD**

Funding to trial the development of a Wearable Apnoea Detection Device, designed to trigger an alarm when breathing stops in SUDEP. Designated where there is doubt whether the specific fundraising purpose was clearly communicated.

**Research**

General research into the causes & prevention of epilepsy deaths.

**Epilepsy Deaths Register**

Funding to develop the Epilepsy Deaths Register and support collaborations to learn from epilepsy deaths. The Epilepsy Deaths Register started in 2013 is a web based data repository enabling reporting of the circumstances and impact of epilepsy deaths.

**Case Worker Project**

To provide support for bereaved families involved in inquests and formal enquiries into sudden deaths.

**Oxon Pilot Project**

To bring lifesaving solutions to local Healthcare professionals and communities in Oxfordshire.

**14 Analysis of net assets between charities**

	<b>SUDEP Action</b>	<b>Epilepsy Bereaved</b>	<b>Total</b>
Debtors	6,567	-	6,567
Cash at bank and in hand	340,610	-	340,610
Creditors	(19,526)	-	(19,526)
Total net assets	<u>327,651</u>	<u>-</u>	<u>327,651</u>

Epilepsy Bereaved had no activity during the year ended 31 March 19 or the comparative year.